

A National Patient-Centered E-Health Solution – The Experience from Down Under To-Date with the Personally Controlled Electronic Health Record (PCEHR)

Completed Research Paper

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Abstract

Given the current pressures on healthcare delivery to be cost effective yet provide high quality, healthcare systems are turning to ICT (information communication technology) to help resolve this conundrum. Such e-health solutions range from being on one-side patient controlled to the other end of the spectrum being provider controlled. However, most agree that these solutions should be patient-centric. Australia has opted for a unique solution in an attempt to have the best of both worlds; i.e, some level of patient control and some level of provider control. This system is known as the PCEHR (personally controlled electronic health record). The following serves to investigate this system and if it is patient centric. In particular, how well patient focus, patient activity and patient empowerment are supported and/or enabled.

Keywords

Healthcare; Healthcare Delivery; Healthcare Operations; Healthcare Management; Personally Controlled Electronic Health Records; PCEHR; E-Health; Electronic Health Record; EHR; Patient-Centered E-Health; PCEH

Introduction

In today's dynamic healthcare environment, governments and healthcare service providers in all OECD countries are facing major challenges of trying to eliminate waste to decrease waiting-room delays and use/over use of unnecessary surgical tools in trying to deliver quality healthcare services (Wickramasinghe et al., 2009). In addition, further pressure is being placed on healthcare service providers as they are being asked to do more to provide a high quality and level of service with very limited resources and in less time (Wickramasinghe and Schaffer 2010). This confluence of factors has led policy makers and healthcare leaders to call for a redesign of healthcare delivery systems that can not only handle multispectral data and disparate information but also can improve the flow of this information between key stakeholders (such as service providers, consumers, government agencies and healthcare managers) to improve health outcomes and quality of care (Mort et al. 2009. Integral to all such redesign is the embracement of some type of Patient-Centric e-health solution (Wickramasinghe and Schaffer 2010).

In Australia, the healthcare system has historically been centered on the practitioners and service providers. This mode of service however, is proving to be costly and very hard to sustain today. Thus, Australia is in the process of a comprehensive healthcare reform to redesign healthcare services and incorporate a patient-centered healthcare agenda to improve healthcare quality, patient access and healthcare sustainability. A key enabler for this redesigned system is an Information Communication Technology (ICT) solution known as the Personally Controlled Electronic Health Records (PCEHR).

Given the importance of the sustainability of the healthcare system and the significant change this redesign has on current and well established healthcare practices, not to mention the current turbulent time of economic downturns, it is not possible to underscore not only what a huge challenge this project is but also that it represents a key paradigm shift for healthcare delivery in Australia. Specifically, the paradigm shift from a service provider-centered system to a patient-centered system requires fundamental changes in the planning, evaluation and delivery of healthcare services. The following serves to evaluate the proposed PCEHR system and thereby answer the research question how/why is the PCEHR a patient-centered national healthcare solution? In so doing it also provides lessons from another country's experiences that are of benefit to all countries currently evaluating options for patient centered e-health solutions.

Background

In order to understand the PCEHR, it is first necessary to briefly understand the Australian healthcare delivery system.

Structure of Healthcare Delivery in Australia

The Healthcare system in Australia is a combination of private and public sector care providers comprising of over 1326 hospitals, which serve around 22.6 million citizens across different geographic and socio-economic settings. Healthcare service delivery and financing is the joint responsibility of federal, state and territory governments through, taxation, Medicare levy and council rates along with some contribution from local governments as well as private health insurance companies and consumers (Heslop 2010; Duckett & Willcox 2011; Willis et al. 2009).

Public hospitals are managed and operated under the ownership of state and territory governments which provide free service at the point of delivery for all Australian citizens. State and territory governments are also responsible for the delivery of community health, aged-care, mental health, patient transport and dental services for mostly free of cost to Australian consumers.

The Commonwealth Government is responsible for healthcare policy development, healthcare service regulation and healthcare funding through the Australian Health Care Agreements (AHCA) to state and territory governments (Willis et al. 2009; Duckett & Willcox 2011). In addition, the Commonwealth Government provides rebates to patients through Medicare Australia a "universal (government) health insurance" system and pharmaceutical benefits scheme (ibid). Finally, the Commonwealth Government regulates the private health insurance industry (ibid).

The complexity of these funding arrangements and interaction between different levels of service providers and consumers in healthcare service delivery is illustrated in figure 1. Figure 1 also serves to highlight the fragmented nature of the Australian healthcare system. In particular, as can be seen in figure 1, healthcare services are provided at different levels and their delivery settings consist of different elements. These can be defined depending on different political, cultural and organisational perspectives (Duckett & Willcox 2011). In the Australian context these represent the three different levels of healthcare service delivery, namely:

Primary Care: A community based first point of interaction between patients and range of healthcare service providers such as GPs, Nurses, family physicians, pharmacist and in some regions clinical officer, Ayurvedic or traditional medicine.

Secondary Care: This is a healthcare service provided by specialist doctors such as gynecologists, cardiologists, endocrinologists. In Australia primary care provider need to give a referral for secondary care provider.

Acute Care: This is a specialised healthcare service provided in hospitals for advanced medical diagnoses, investigation and treatments.

The Australian model of healthcare is predominantly hospital-centric and there is a growing concern that these kinds of models are not sustainable in long run. Hospital-centric or acute healthcare service delivery models are complex and costly and need to be reviewed (Rhyne 2008; S. R. Leeder & Alexander 1992; Haas 2009; DoHA 2010; DoHA 2009). For example people with mental health and chronic disease might

need lifelong support and care most of which can be provided through self-management or a primary healthcare system, which would be cost-effective and would help to reduce burden from hospitals (Willis et al. 2009) but more importantly also better suited to the patients' needs.

The transformation from a hospital-centric healthcare system to a primary healthcare model has been realised through the Australian healthcare reform and a comprehensive healthcare reform strategy has been introduced in 2010 (DoHA 2010). Before we take a deeper look into the Australian healthcare reforms it is important to highlight the key issues and challenges driving these reforms.

Challenges Faced By the Australian Healthcare System

Like all OECD countries, the Australian healthcare system is confronting major healthcare funding and delivery challenges. A further challenge relates to the fact that, even though the healthcare system in Australia has been considered highly ranked internationally because of high life expectancy and low infant mortality (Heslop 2010; Armstrong et al. 2007), this ranking is now under strain as the system is hard-pressed by an ageing population, increased prevalence of chronic disease and its burden on healthcare service, and outdated infrastructure and Organisational models of healthcare delivery (Armstrong et al. 2007). In addition, healthcare inequalities also persist in Australia and the gap of service accessibility between rich and poor is widening markedly (Duckett & Willcox 2011).

A report by the Australian Bureau of statistics (ABS) has predicted that by 2020; 16% of Australians would be aged 65 or over and this could rise to 27% by 2101 because of low fertility rates and increased life Expectancy (ABS 2008). This can put enormous pressure on healthcare budgets (WHO 2006), and currently healthcare expenditure is increasing with Australia already spending 9.6% of its GDP on healthcare and this is expected to rise by 16% to 20% if current trends for healthcare demands continue (DoHA 2010).

Another devastating effect for Australia, since although it has a two tier healthcare system the dominant system is the government or national healthcare system, would be a decrease in the working population and shortage of workforce in all areas including healthcare that will lead to reduced tax collection which is a major source of healthcare funding (Rhyne 2008; DOHA 2010; Haas 2009; Jones 2011).

Increased prevalence of chronic disease is another major issue especially with the increasing ageing population incidence of chronic diseases; an estimated 25% of the Australian population is suffering from chronic illnesses which is increasing at a very rapid pace (AIHW 2010). Persistent health inequalities, rapid pace of inventions into new technologies and medicines and consumer expectations are also putting more pressures for increased healthcare spending (Productivity Commission 2005).

One way of handling these issues is to reorient the healthcare system towards prevention rather than cure and community based self-management care systems for chronically ill patients by involving them in their care management process. This would reduce the burden from hospitals and health budgets. For this to be successful it is necessary to have a nationwide health information technology solution which has capacity to decrease health disparities and improve self-management of healthcare (Shields et al. 2007), healthcare efficiency, quality and safety (Fiscella & Geiger 2006; Wise & Bankowitz 2009).

Another major issue with the Australian healthcare delivery system is its fragmented nature. The system operates as a disintegrated and disparate set of services. In particular, there is no coordination between primary healthcare service providers and acute healthcare service providers (Duckett & Willcox 2011). Thus, there is a greater need of coordination between and across different elements and areas of the healthcare system for fast and cost effective service delivery and again without a nationwide technology solution this is not possible. (DoHA 2009).

Yet another major issue is the inability of collecting and sharing health information of patients among different sectors of healthcare service (Duckett & Willcox 2011; Heslop 2010; Jones 2011). The current situation can pose a very serious risk of diagnosis and treatment errors, increase waiting times for referrals, increase diagnostic test duplications, slow down hospital discharges, and can have adverse effects on administration staff work efficiency (Heslop 2010; Jones 2011).

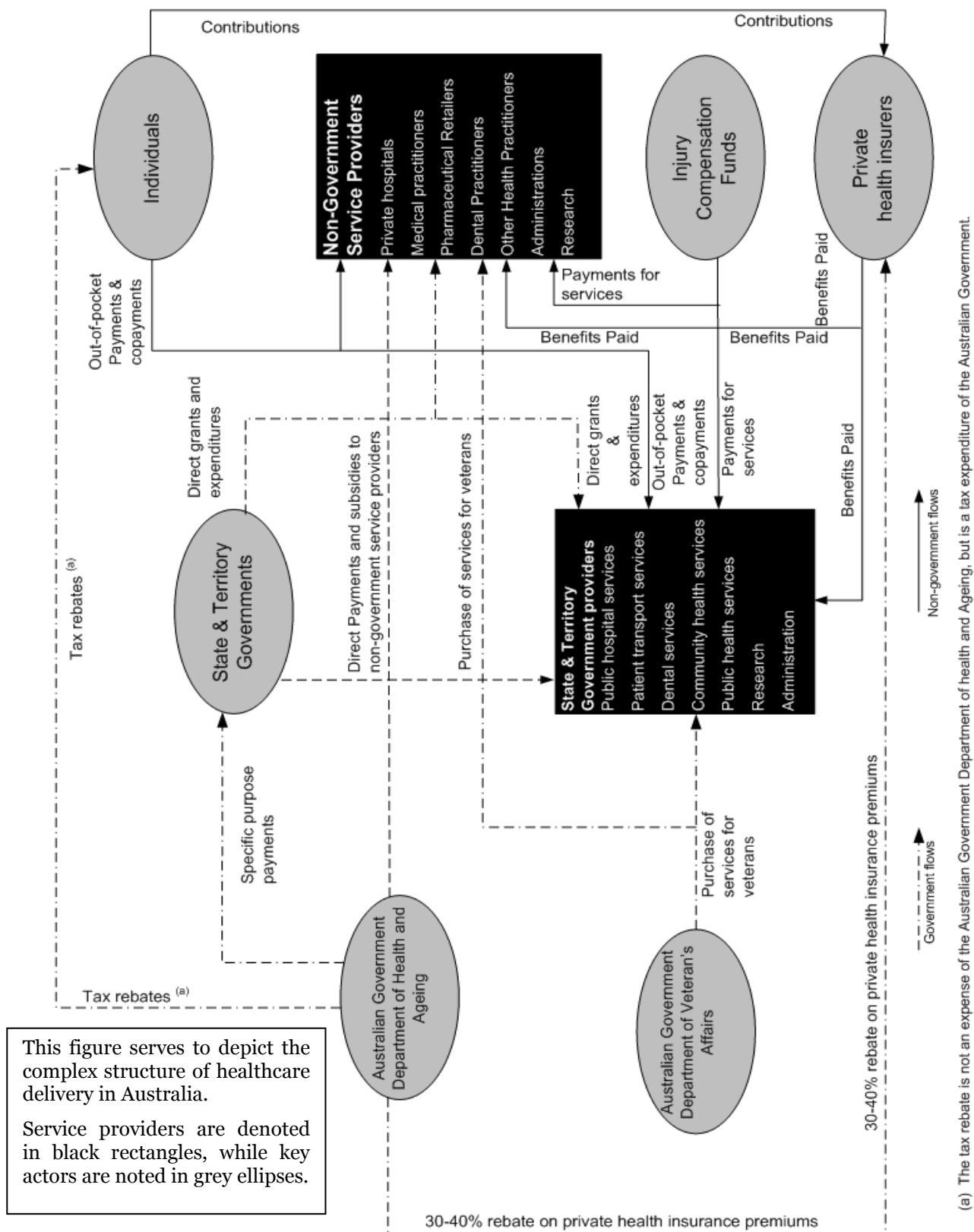


Figure 1: The Structure of Australian healthcare system and its flow of funds (AIHW 2010, p.4)

A report prepared by Deloitte (Deloitte 2008) suggests that the meaningful improvements in any performance can only be achieved if any reform can bring about significant improvements in the way information in the healthcare sector of Australia is collected, used, shared and disseminated. In order to achieve this, a meaningful use of Information Technology (IT) is proposed by many; especially since the current state of Information Communication Technologies (ICT) use in Australian healthcare sector to date has been woefully inadequate (Deloitte, 2008).

The Personally Controlled Electronic Health Record (PCEHR)

To address the aforementioned challenges, the Australian government decided it would be prudent to introduce a national e-health solution. The terminology adopted in Australia for electronic record keeping and its e-health solution is known as the Personally Controlled Electronic Health Record (PCEHR) which sits between an individually-controlled health record and a healthcare provider health record (NEHTA and DoHA 2011; figure 2). Thus, the PCEHR has a shared use and mixed governance model (NEHTA and DoHA 2011; figure1).

Specifically, the PCEHR is a patient-centric secure repository of electronic health and medical records of an individual's medical history that would act as a hub for linking hospital, medical and pharmaceutical systems using a patient unique identifier (NHHRC, 2009:134). One of its key features is that it captures information from different systems and presents this information in a single view to consumers and authorised service providers for better decision making about health and service delivery (NEHTA & DoHA 2011). This is thus a hybrid health information system that integrates web based personal health records with a clinical electronic health record system and allows shared access to both consumers and healthcare providers based on a shared responsibilities and mixed governance model. (Leslie 2011).

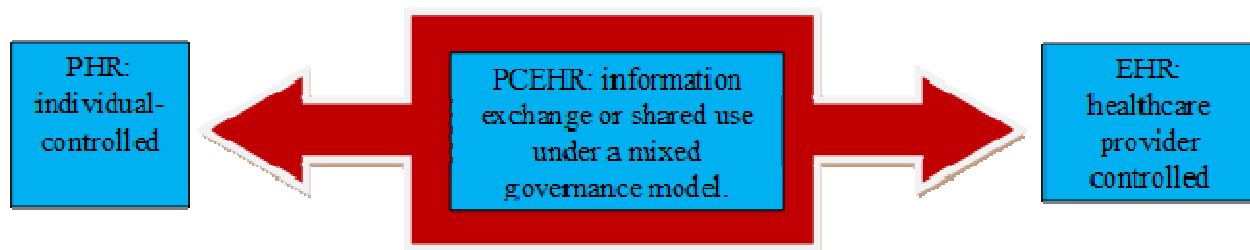


Figure 2: The position of the PCEHR in the e-health solution spectrum

As we can see from the preceding overview, the PCEHR is a patient-centric system where technology is going to be implemented in a complex clinical and organisational environment and users are going to include a different set of stakeholders including healthcare service providers, healthcare managers, government bodies, healthcare pressure groups and most importantly patients.

Further, the PCEHR is a patient centric system and is a model for essentially engaging patients in their healthcare and empowering them in this undertaking. The PCEHR utilises advances in technology most notably that of web 2.0 which makes it possible to engage users by providing them interactive user interfaces.

PCEHR, a patient-Centered E-health solution

To understand the nature of the PCEHR and thereby demonstrate how/why it is a patient-centered solution, it is first important to understand the definition of patient-centered ehealth (PCEH). To illustrate what is PCEH we use Wilson's definition (Wilson, 2009).

According to (Wilson, 2009) PCEH is a combination of three key themes. These themes were used as a priori themes in our data analysis are defined below:

Patient-focus: The primary goal of the development of patient-centered ehealth application is to satisfy the needs and requirements of the patient.

Patient-Activity: patient-centered ehealth applications will allow patients to participate actively in their healthcare services. Further it will allow them to have full access to the information electronically and can securely provide information and consume information whenever, where ever it is needed.

Patient-empowerment: patient-centered ehealth applications goal is to empower patients with their healthcare decision making process. They can make informed decisions based on available data about their health and medication.

PCEH then is different from traditional HIS solutions and places emphasis on a patient focused perspective as compared to traditional health information systems (HIS) in many ways. The primary, traditional goal of HIS is to empower health service providers, healthcare agencies and hospitals to help them make better and informed decisions about patient treatments, whereas the primary goal of a PCEH paradigm is to empower patients by giving them responsibility of managing their health based on health records information (Dawson, Tulu, & Horan, 2009). The key differences between HIS and PCEH are illustrated in a table 1. Further, based on our data analysis it is also possible to compare the PCEHR with the key concepts of the traditional PCEH and thereby show how the PCEHR is indeed a patient-centered ehealth solution with shared governance and hence also distinct from traditional HIS.

	Traditional Health IS	Traditinal PCEH	PCEH with Shared Governance
Emphasis	Record-keeping	Access to patient information	A controlled access to patient health information by emphasising “personally controlled” by patient under a shared governance model.
Users	GPs, Hospital staff, Nurses,	Patient and service providers	Patient, patient’s relatives (if they have been granted access authorisation) and service providers
Interaction	Provider \rightleftarrows Patient	Provider \rightleftarrows \rightleftarrows Patient	Provider \rightleftarrows \rightleftarrows Patient
Supports	Provider activities	Patient health management	Patient health management, EHR, pathology repository, medicine repository, consumer portal, web-based service provider portal, service provider local clinical system and hospital clinical system.
Services available	At hospital location	Anywhere, anytime	Web based portal available anywhere and anytime.
System accessibility	Accessed locally	Accessed globally	Accessed globally
Patient access	Patient has only indirect access to patient information	Patient has direct access to patient information	Patients have control over the record can access, change and add information into their record.

Table 1: Comparison of Traditional HIS, PCEH and PCEHR (Adapted from Wilson, 2009)

As we can see from Table 1, the PCEHR is designed to put patients at the centre of the system. Patients have been empowered by giving them the full control over the system and explicit rights to control the flow of information. It further facilitates patients to manage their health, find information relating to their condition and interact with their service provider electronically. Figure 3 provides a complete overview of PCEHR which also serves to provide the logical flow and design of the system. Further this figure depicts

the logical structure for the PCEHR. As can be seen there are both provider and consumer access which illustrates the shared governance nature of the system.

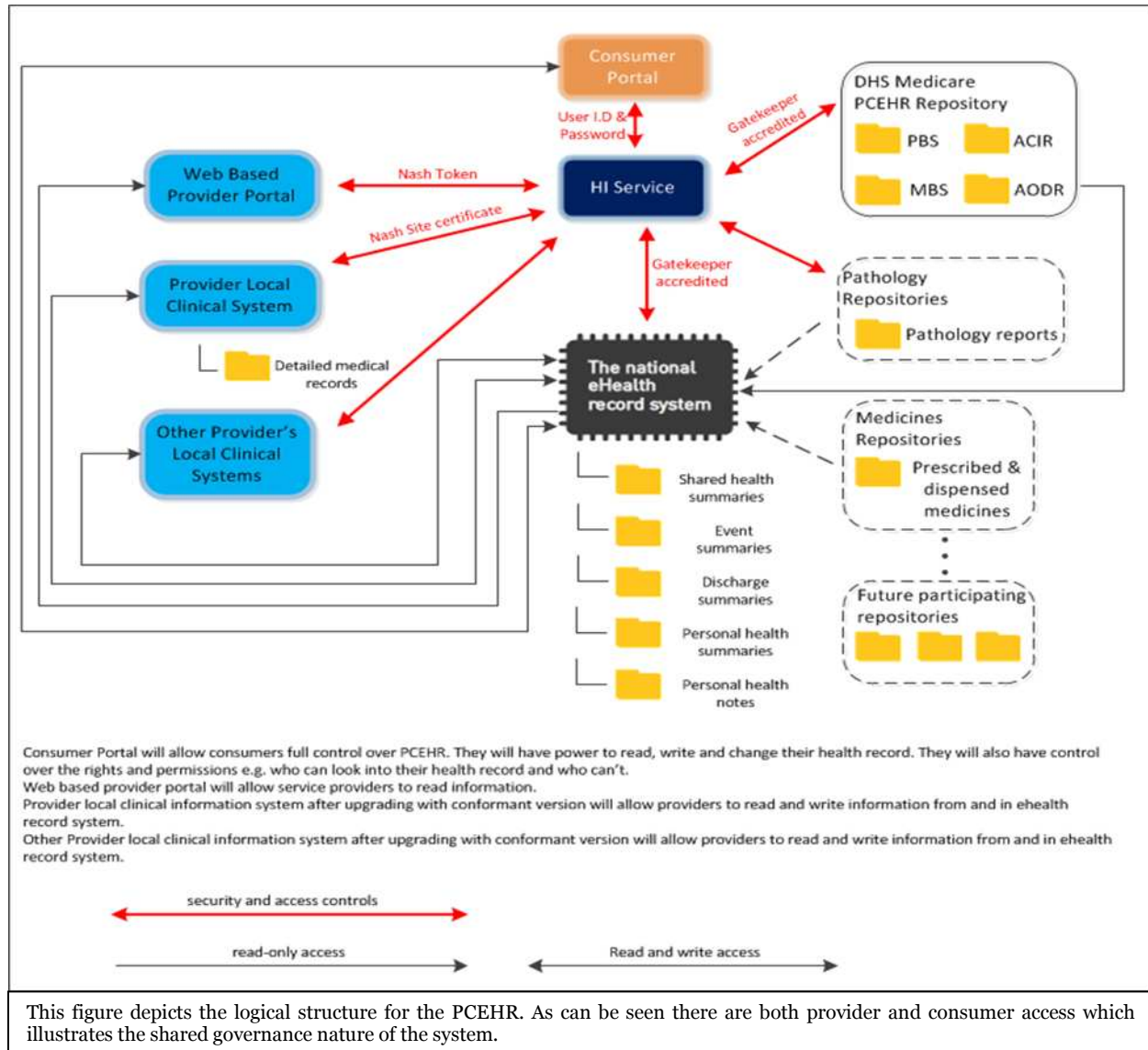


Figure 3: Overview of PCEHR (Adapted from NEHTA 2012)

Objective of the Study

Given the importance of the PCEHR to Australia it is important to make an assessment of its importance as an e-health solution. One key success factor is connected with its level of patient centeredness.

As noted by Wilson (2009) being patient centered is an important success criterion of e-health solutions. Thus we have set out to answer the research question “How/Why is the PCEHR a patient-centered national healthcare solution?”

Methodology

Based on the criteria given by Yin (2010); the choice of this research study is a qualitative single-case study research because this is an exploratory study of a new phenomenon of a healthcare information

system implementation; the Personally Controlled Electronic Health Record and how it can transform the healthcare sector of Australia to smooth, affordable and efficient healthcare service and delivery. Qualitative research is holistic, humanistic, and interactive, it can provide more support to focus on the study of a complex phenomenon of human and system interaction and relationship; as in our case of a health information system (i.e., the PCEHR) (Creswell & Oaks, 2008; Yin 2010; Yin 2009). Qualitative research can provide deeper understanding of the phenomenon as compared to a quantitative study because of the exploratory nature of the study and focus which would not be on quantitative measures (Trochim & Donnelly 2008).

E-health is a contemporary issue, not only in Australia but globally, and the boundaries between phenomenon and context are not clear. This is evident by the lack of clarity about the nature of different systems (PHR, EHR, and PCEHR) and their meanings and use and their implementations and adoptions and the dynamic nature of healthcare systems operations. Therefore, the method for this study will be an exploratory case study based on qualitative data collection and analysis techniques.

Data was collected by employing a variety of data collection techniques. This included in-depth, open-ended unstructured interviews with key informants from different stakeholders in the PCEHR Project. These stakeholders included General Practitioners (GPs), Doctors in hospitals, nurses, NEHTA (national e-health transition authority – the organization charged with designing and deploying the PCEHR) representatives, Pharmacists and representatives of healthcare organisations. In addition, a random sample from the general public was surveyed to understand the patient centeredness of the system and public's opinions. Further, these interviews helped to develop an in-depth understanding of contextual issues, constraints and inspirations to generate themes that are relevant to the need and use of health information technology in health services and delivery. Finally, triangulation of data was achieved by analysis of published reports and printed news reports. Actor Network Theory (ANT) was used to provide a rich and robust theoretical lens by which to systematically observe and analyses the interactions of key actors at the macro, meso and micro level. Further ANT was used to develop themes and assist with the coding of the data.

Actor Network Theory Based Analysis

In depth coding and thematic analysis of interview and survey data was performed and Actor Network Theory (ANT) was used to inform this analysis. At the completion of the analysis several emergent themes were identified. We now present 4 key emergent themes as follows:

Actors' interactions through the PCEHR – this included clinicians, patients and other stakeholders.

Perception and cognition – many people held strong opinions regarding the PCEHR and its role in the Australian healthcare system.

Organisational change – several stakeholders noted that the PCEHR was a disruptive technology that had far reaching impacts and implications for many areas of operations within healthcare organizations.

Competence – many people noted that now clinician and patient users need to be more technology savvy to successfully navigate through the PCEHR system.

To assist with our analysis of this rich data we drew upon Actor Network Theory (ANT) (Latour, 1996; 2005; Law and Callon, 1992). We present a summary of the key findings below.

Actors' Interactions through PCEHR

Using ANT it was possible to understand the multiple interactions of human and technology actors in connection with the PCEHR. Importantly these interactions took place at the micro, meso and macro levels as shown in Figure 4. This figure depicts macro, meso and micro level actors and their activities. Further it can be seen here that PCEHR is present at all three levels and serves to connect and bridge all three levels of domains.

The current practices of ICT use in the healthcare sector of Australia before the implementation of PCEHR vary from practice to practice. These practices have a huge impact on the PCEHR implementation and adoption. For example, if GPs are currently using communication technologies they are more inclined

towards adoption as they think it would be a lesser learning curve for them. A similar situation also is true for patients if they are technology savvy users. What our analysis shows is the importance of the interaction between all three levels highlighted in figure 4 which are critical for the success of this implementation and ongoing use. Specifically, it was possible to observe activates that satisfied the three tenants of being patient-centered i.e.

- Patient focus- screens and views are designed to highlight patient issues.
- Patient activity- patients can add and change data to show how they progress with a specific treatment plan.
- Patient empowerment- it is possible for patients to access information to help them make informed decisions related to their health and wellness.



Figure 4: Interactions of Actors with the PCEHR

Perception and Cognition

Perception allows humans to sense, isolate and acknowledge physical input, whereas cognition refers to a higher level of mental functions including language, information processing, strategic planning and development of rules, learning and knowledge gaining and judgment (Hasler, 1996; McFarland & Cacace, 1999; Sawyer, 1997).

During the survey and interview sessions it was observed that the majority of users (service providers and general public) were positive that the system can improve patient care and can help service providers with readily available information for informed decision making and superior healthcare as one GP stated:

“PCEHR is not yet fully implemented and do not have all the required information of patients at the moment but I can see this system have lot of potential and I am really excited about it”.

Another doctor expressed his views as:

“and once we have an electronic record of their personal history, I think time spent can be more usefully done so by concentrating on their healthcare and their management, rather than trying to glean information which is relevant from various sources”.

With regards to the general public, their perceptions about the system would play a key role in the success of the system. The majority of participants thought it would be very helpful to use other means of communication (e-mail, web portals) to interact with their healthcare service providers. Further respondents opinions about the availability of their health record was positive as one of them noted:

“It would be helpful for us and our healthcare service providers to be able to access our health and medical record electronically, even if we change our doctor”.

However, they also expressed their concerns, that technology can and will radically change every aspect of patient care and is a must have next step. The first impressions are always very critical, they shape people’s attitude towards the system based on its functionality and ease of use. Frustrations can play critical role in decision making process and can lead to rejection when expectations are not met; problems are not resolved effectively and in timely manners and support are not available when needed. As one doctor expressed:

“The time I need to spend to use this system will have impact on my decision to adopt this system, I think if this system forces me more towards data entry rather than taking care of my patient I will reject this system”.

Organizational change

Health information system implementations are said to enhance the work flow and speed up the care process in healthcare services settings (Mort et al. 2009; McLaughlin & Kaluzny, 2006; Wickramasinghe and Schaffer 2010); But these interventions are not simple and easy propositions. These interventions need very thoughtful process reengineering and change management. Users can and will resist any change in the form of new technology implementations. In the case of the PCEHR, consumers were very frustrated because of poor problematisation (a term from ANT to refer to the framing of the problem). At this stage the problem was not properly identified even though actors were identified but their interests and needs were not identified and/or properly framed. Therefore, it was observed that identifying the primary actor was very hard – is it the patient or the clinician for example.

It was also highlighted during data analysis that data entry and information retrieval from/to the PCEHR is very slow because of the difficulty in finding the correct information, selecting the correct charting place, difficult user interface, multiple screens, difference in terminologies and lack of inter-migration with other healthcare IT systems.

These issues slowed down the delivery of care, leading some to dislike the system right from the beginning, creating uncertainty and poor clinical documentation. As described by one nurse:

“I mean, I work in the emergency department. All my work in the emergency – Not all but most of my work in the emergency department is around, “Well, what tablets are you taking?” “What happened to you last week?” Stuff like that. Today, I had some – A guy comes in to see me and he’s had an operation and he’s had tests and I haven’t got any of them because they’re off somewhere in Never-Never Land. I would have liked to have read them. It’s not enough for me to say, “Go away and get them.” So I’m making decisions based on imperfect information.”

Thus, appropriate change processes are needed in key organisational activities within healthcare organizations for the system to be truly beneficial and meaningful.

As one of the interviewees expressed:

“It’s all about change and adoption and engagement with people and with clinicians - that’s much more complex than understanding their workflow.”

Competence

The intention of PCEHR implementation is reasonably sound, but not sufficiently focused on clear outcomes as can be seen in Victorian government’s response to concepts of operations. Further, it is assumed that all users (clinician and patients) have the necessary technology skills to navigate through the system. Looking at global examples, countries are moving towards better integrated care, better coordinated care and that is clearly needed in Australia too. Australia’s initial responses are not enough. Furthermore, the idea of consumer empowerment is a very powerful idea. People can self-manage their healthcare activities because they have got access to the right information. However, they also need the right skills and support structures. So a real concern with the PCEHR implementation is two-fold. First, most jurisdictions concern is that Commonwealth has not realised the scale of the project they are taking on as one interviewee explained

“The Commonwealth hasn’t had enough appreciation of the scale of what it’s taking on. It’s focused on what we’re gonna do at the centre, whereas for that to work, there’s a whole bunch of stuff you have to do around the periphery”.

Secondly, the government tends to think of the PCEHR as being at the centre but as we can see from figure 3 PCEHR is clearly a complimentary to the core of healthcare delivery and operations.

To be truly patient centered it must also provide the necessary structures and support for patients.

Discussion and Conclusions

This paper has identified the major challenges facing the Australian healthcare system, and described how, in an attempt to address these challenges and provide all Australians with cost effective quality healthcare delivery, the Australian Government has developed the nationwide e-health solution, the PCEHR. Further, the paper notes that the PCEHR is the key foundation of Australian healthcare reform. Moreover that it will attempt to play an important role in reducing costs and improving quality of care. It is envisaged that the PCEHR will improve the interaction between service providers and patients and will empower patients with their own healthcare related information to make informed decisions.

The paper has shown that PCEHR is indeed a nationwide patient-centered e-health solution, for many reasons but most especially because it clearly subscribes to-support and enables a patient focus, patient activity and patient empowerment, three critical themes of patient-centered ehealth. Hence, the posed research question has been answered. On the other hand, the paper has also identified that the implementation and adoption of the PCEHR is challenging and requires substantial changes in the planning, evaluation, and delivery of health services, a healthcare service that has traditionally revolved around service providers and an acute healthcare system.

We note that IT based interventions to reform healthcare services for the improvements of health outcomes are increasing globally. Specifically, to name few, the e-health cards (eHC) in Germany and UK’s program under NHS National Program for IT (NHS Connecting for Health) as well as the many initiatives being developed currently in the US. We believe there are generalisable lessons for all healthcare systems concerning trying to design and develop PCEH solutions and it behoves all to learn from the Australian experience. Specifically, the PCEHR in Australia serves to demonstrate that it is possible to develop a nationwide patient-centered e-health solution that can combine government or public healthcare models and private healthcare models. In addition, it also demonstrates that it is possible to have a large scale PCEH with a shared governance model that caters to various groups in the population including aged, minorities, disabled and less computer savvy individuals and thereby it is possible to try to provide patient-centered ehealth solutions to all citizens. Naturally, its full success will be seen in the fullness of time. However, we believe there already exist many cases that can be beneficial to other healthcare systems as they implement their chosen e-health solution.

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